

	<p><b>(Affix Label Here)</b></p> <p>Participant ID: _____</p> <p>Participant Name Code: _____</p>	<p>Date Form Filled Out:</p> <table style="margin: auto;"> <tr> <td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td> </tr> <tr> <td>d</td><td>d</td><td>M</td><td>M</td><td>M</td><td>y</td><td>y</td><td>y</td><td>y</td> </tr> </table> <p>(e.g., 10JUN2005)</p> <p>Interviewer Code: <input type="checkbox"/><input type="checkbox"/><input type="checkbox"/></p> <p>Circle Field Center Location:</p> <p style="text-align: center;"> <span style="margin-right: 20px;">BU</span> <span style="margin-right: 20px;">CU</span> <span style="margin-right: 20px;">DK</span> <span>UP</span> </p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	d	d	M	M	M	y	y	y	y
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## Dementia Questionnaire (Phase II Follow-Up)

**Note to Interviewer:** This form can only be administered via DFR/Proxy. For the first year this form is administered, omit using the phrasing in brackets [i.e., since date of last interview].

What is the individual's relationship to the Study Participant?

- 1 .....Spouse
- 2 .....Child (Daughter/Son)
- 3 .....Sibling (Brother/Sister)
- 4 .....Niece/Nephew
- 5 .....Other: \_\_\_\_\_

**MEMORY/COGNITION:** [Since *[date of last interview]*,] does *[participant name]* have any problems with the following in a way that interferes with daily living and is out of the ordinary for him/her?

1. Memory problem (get specific examples and record below)

- 1 ..... Yes
  - 0 ..... No
  - D ..... Don't Know
  - R ..... Refused
- Date of Onset: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ \_\_\_     **OR**     Age of Onset: \_\_\_ \_\_\_ \_\_\_  
*(If "Don't Know" = D; "Refused" = R)*

2. Confusion (examples).

- 1 ..... Yes
  - 0 ..... No
  - D ..... Don't Know
  - R ..... Refused
- Date of Onset: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ \_\_\_     **OR**     Age of Onset: \_\_\_ \_\_\_ \_\_\_  
*(If "Don't Know" = D; "Refused" = R)*

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

3. Trouble remembering people's names.

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

4. Trouble recognizing family members.

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

5. Trouble finding way on familiar streets

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

6. Trouble finding way about indoors.

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

7. Remembering a short list of items.

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

**Interviewer:** If the participant has answered "Yes" to any of Q1-7 above, continue with Q8; otherwise, please skip to Q10.

8. Did the trouble begin suddenly (OVERNIGHT) or slowly?

- <sup>1</sup> ..... Suddenly
- <sup>0</sup> ..... Slowly
- <sup>D</sup> ..... Don't Know
- <sup>R</sup> ..... Refused

9. [Since *[date of last interview]*,] have the memory problems changed over time?

- <sup>0</sup> ..... No change
- <sup>1</sup> ..... Yes, memory has improved
- <sup>2</sup> ..... Yes, steady decline over time
- <sup>3</sup> ..... Yes, sudden decline(s)
- <sup>D</sup> ..... Don't Know
- <sup>R</sup> ..... Refused

**NOTES AND EXAMPLES:** \_\_\_\_\_

**EXPRESSION:** [Since *[date of last interview]*,] does *[participant name]* have any problems with the following that seems to be out of the ordinary for him/her:

10. Ever have trouble finding the right word or expressing self?

- <sup>1</sup> ..... Yes
- <sup>0</sup> ..... No
- <sup>D</sup> ..... Don't Know
- <sup>R</sup> ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ OR Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

11. Talking less than *[he/she]* used to?

- <sup>1</sup> ..... Yes
- <sup>0</sup> ..... No
- <sup>D</sup> ..... Don't Know
- <sup>R</sup> ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ OR Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

12. Have a tendency to dwell in the past?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

**DAILY FUNCTIONING:** [Since *[date of last interview]*,] does *[participant name]* have any problems with the following:

13. Trouble with household tasks (examples)?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

14. Trouble handling money (examples)?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

15. Trouble grasping situations or explanations?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

16a. Does *[he/she]* work outside the home?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

**Skip to Q16c**  
**Skip to Q16b**  
**Skip to Q16b**  
**Skip to Q16b**

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

16b. Is [*he/she*] retired?

- 1 ..... Yes
- 0 ..... No
- W ..... Never Worked
- D ..... Don't Know
- R ..... Refused

**Skip to Q17**

**Skip to Q17**

**Skip to Q17**

**Skip to Q17**

Age: \_\_\_\_ \_\_\_\_ \_\_\_\_ (Convert Age to Code Year)  
(If "Don't Know" = D; "Refused" = R)

**AND** Year: \_\_\_\_ \_\_\_\_ \_\_\_\_ \_\_\_\_

16c. Does [*he/she*] have difficulty at work?

- 1 ..... Yes
- 0 ..... No/Not Applicable
- D ..... Don't Know
- R ..... Refused

Year: \_\_\_\_ \_\_\_\_ \_\_\_\_ \_\_\_\_ (If "Don't Know" = D; "Refused" = R)

17. Trouble with dressing or self-care (examples)?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ \_\_\_\_ / \_\_\_\_ \_\_\_\_ \_\_\_\_ \_\_\_\_ **OR** Age of Onset: \_\_\_\_ \_\_\_\_ \_\_\_\_  
(If "Don't Know" = D; "Refused" = R)

18. Trouble feeding self?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ \_\_\_\_ / \_\_\_\_ \_\_\_\_ \_\_\_\_ \_\_\_\_ **OR** Age of Onset: \_\_\_\_ \_\_\_\_ \_\_\_\_  
(If "Don't Know" = D; "Refused" = R)

19. Trouble controlling bladder and bowels?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ \_\_\_\_ / \_\_\_\_ \_\_\_\_ \_\_\_\_ \_\_\_\_ **OR** Age of Onset: \_\_\_\_ \_\_\_\_ \_\_\_\_  
(If "Don't Know" = D; "Refused" = R)

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

20. Agitation and nervousness?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_      **OR**      Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

NOTES AND EXAMPLES: \_\_\_\_\_

**RECOGNITION OF PROBLEM:**

***Interviewer Note:*** If the participant has answered "YES" to any of Q1-7 or Q10-20 above, ask Q21-25b below; if all responses above are "NO", Skip to Q26a.

21. Who was the first person to notice something wrong?

- 1 ..... Self
- 2 ..... Spouse
- 3 ..... Sibling
- 4 ..... Child
- 5 ..... Home Attendant
- 6 ..... Physician
- 7 ..... Other: \_\_\_\_\_
- D ..... Don't Know
- R ..... Refused

22. What was noticed? \_\_\_\_\_

23. When was the last time [he/she] seemed to be really well, [his/her] old self?

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_      **OR**      Age of Onset: \_\_\_\_

(If "Don't Know" = D; "Refused" = R)

24a. Did [participant name] see a doctor for any of these problems [since [date of last interview]]?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

24b. If "Yes", what cause was given? \_\_\_\_\_  
\_\_\_\_\_

25a. Did [*participant name*] see a Neurologist for any of these problems [since [*date of last interview*]]?

- I ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

25b. If "Yes", was the diagnosis Alzheimer's Disease?

- I ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

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**STROKE:** [Since [*date of the last interview*],] did [*participant name*] have:

26a. A Stroke?

- I ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

**Skip to Q27a**  
**Skip to Q27a**  
**Skip to Q27a**

Date of Onset: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ \_\_\_ \_\_\_ **OR** Age of Onset: \_\_\_ \_\_\_ \_\_\_  
(If "Don't Know" = D; "Refused" = R)

**Interviewer:** If "Yes", ask the following:

26b. More than one (1) stroke?

- I ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ \_\_\_ \_\_\_ **OR** Age of Onset: \_\_\_ \_\_\_ \_\_\_  
(If "Don't Know" = D; "Refused" = R)

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

26c. One side of body suddenly weaker than other side; paralysis?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ \_\_\_ \_\_\_    **OR**    Age of Onset: \_\_\_ \_\_\_ \_\_\_  
 (If "Don't Know" = D; "Refused" = R)

26d. Sudden loss of sensation on one side of body?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ \_\_\_ \_\_\_    **OR**    Age of Onset: \_\_\_ \_\_\_ \_\_\_  
 (If "Don't Know" = D; "Refused" = R)

26e. Change in speech with slurring?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Date of Onset: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ \_\_\_ \_\_\_    **OR**    Age of Onset: \_\_\_ \_\_\_ \_\_\_  
 (If "Don't Know" = D; "Refused" = R)

26f. Which symptom was most prominent?

- 1 ..... Weakness/Paralysis
- 2 ..... Loss of Sensation
- 3 ..... Slurred Speech
- 4 ..... Other: \_\_\_\_\_
- D ..... Don't Know
- R ..... Refused

26g. Did the symptoms persist longer than a day?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused



26h. Did the symptoms:

- 1 ..... Become Worse
- 2 ..... Improve
- 0 ..... Stay Stable Over Time
- D ..... Don't Know
- R ..... Refused

26i. Did a doctor give a diagnosis of stroke?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

26j. Did a doctor say it was a hemorrhage or bleeding inside the brain?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

***Interviewer Note:*** If there is both stroke (Q26a=Yes) and memory loss (Any of Q1-7 or Q10-20=Yes), explain that they are both common conditions and elderly people can get both without being related, we need to find out if the memory loss preceded the stroke, was caused by the stroke, or just occurred by itself; otherwise, skip to Q27a.

26k. Did the memory loss you described occur before or after the stroke?

- 1 ..... Before **Skip to Q27a**
- 2 ..... After
- D ..... Don't Know **Skip to Q27a**
- R ..... Refused **Skip to Q27a**

***Interviewer:*** If the memory loss occurred **after** the stroke, ask the following:

26l. How long after the stroke did [*participant name*] begin to show memory loss or have other problems with daily functioning?

- 1 ..... Within the first 3 months
- 2 ..... Between 3 and 6 months
- 3 ..... After 6 months
- D ..... Don't Know
- R ..... Refused

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

27a. [Since [*date of last interview*],] does [*participant name*] have a drinking problem or a history of alcoholism?

- 1 ..... Yes
- 0 ..... No **Skip to Q28**
- D ..... Don't Know **Skip to Q28**
- R ..... Refused **Skip to Q28**

**Interviewer:** If "Yes", ask the following:

27b. Was this problem diagnosed by a doctor?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

27c. Did memory problems accompany drinking problems?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

27d. When did the drinking problem begin?

Date of Onset: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **OR** Age of Onset: \_\_\_\_  
(If "Don't Know" = D; "Refused" = R)

27e. How long (in years) did this problem continue? \_\_\_\_ Years (*Don't Know*=D; *Refused*=R)

27f. Ever receive medications or other prescriptions?

- 1 ..... Yes
- 0 ..... No **Skip to Q28**
- D ..... Don't Know **Skip to Q28**
- R ..... Refused **Skip to Q28**

27g. If "Yes", what [*was/were*] the treatment(s) given?

27g.1. Counseling?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

27g.2. Medication?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

27g.3. Hospitalization?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

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**DEPRESSION:** [Since *[date of the last interview]*,] does *[participant name]* have:

28. Depression (e.g. sad, withdrawn, less talkative, unable to sleep, frequent crying)?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

29. A change in personality?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

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**OTHER INFORMATION:**

30. Does *[he/she]* drive?

- 1 ..... Yes
- 0 ..... No
- D ..... Don't Know
- R ..... Refused

**Skip to Q33**  
**Skip to Q33**  
**Skip to Q33**

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

31. Is *[he/she]* having any problems driving?

- 1 ..... Yes
- 0 ..... No **Skip to Q36**
- D ..... Don't Know **Skip to Q36**
- R ..... Refused **Skip to Q36**

32. What type of problems?

- 1 ..... Gets Lost/Confused
- 2 ..... Poor Eyesight
- 3 ..... Illness
- 4 ..... Bad Coordination; Bad Reaction Time; Bad Reflexes
- 5 ..... Frequent Accidents
- 6 ..... Fear/Nervous Driving
- 7 ..... Other Cognitive Problems: \_\_\_\_\_
- 8 ..... Other: \_\_\_\_\_
- D ..... Don't Know
- R ..... Refused

33. Did *[he/she]* stop driving?

- 1 ..... Yes
- 0 ..... No/Not Applicable (never drove) **Skip to Q36**
- D ..... Don't Know **Skip to Q36**
- R ..... Refused **Skip to Q36**

34. Why did *[he/she]* stop driving?

- 1 ..... Gets Lost/Confused
- 2 ..... Poor Eyesight
- 3 ..... Illness
- 4 ..... Bad Coordination; Bad Reaction Time; Bad Reflexes
- 5 ..... Frequent Accidents
- 6 ..... Fear/Nervous Driving
- 7 ..... Other Cognitive Problems: \_\_\_\_\_
- 8 ..... Other: \_\_\_\_\_
- D ..... Don't Know
- R ..... Refused

35. When did *[he/she]* stop driving?

Day: \_\_\_ \_\_\_ Month: \_\_\_ \_\_\_ Year: \_\_\_ \_\_\_ \_\_\_ \_\_\_

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

36. How often do you have contact with *[him/her]*?

- 1 ..... Live Together
- 2 ..... Daily
- 3 ..... 3 or More Times per Week
- 4 ..... Less than 3 times per Week
- D ..... Don't Know
- R ..... Refused

37. Most frequent type of contact?

- 1 ..... Mostly In-Person
- 2 ..... Mostly Phone
- 3 ..... Both
- 4 ..... Other
- D ..... Don't Know
- R ..... Refused

***Interviewer Note: Please answer the following question based on your judgment of the DFR's responses to this questionnaire.***

38. On the whole, how reliable do you think the DFR's responses were to this interview?

- 1 ..... Very Reliable
- 2 ..... Fairly Reliable
- 3 ..... Not Very Reliable
- D ..... Don't Know

***THANK YOU VERY MUCH!!***